



# Building FASD State Systems Meeting Proceedings

San Francisco, California • May 9-11, 2006



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Substance Abuse and Mental Health Services Administration  
[www.samhsa.gov](http://www.samhsa.gov)



SAMHSA  
Fetal Alcohol Spectrum Disorders  
Center for Excellence

## Introduction

The Substance Abuse and Mental Health Services Administration (SAMHSA) Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence convened the fourth “Building FASD State Systems” (BFSS) meeting in San Francisco, California, on May 9 through 11, 2006. The BFSS meetings are designed to facilitate the creation and enhancement of comprehensive systems of care for FASD. They are part of the SAMHSA FASD Center’s response to its legislative mandate to provide technical assistance (TA) to communities developing systems of care.

### Tuesday, May 9, 2006

On the evening of May 9, attendees participated in an opening reception and display session during which groups shared posters or materials about the FASD activities in their States. Attendees learned about effective strategies and networked with one another. Afterward, Ms. Joyce Holl, Executive Director, Minnesota Organization on Fetal Alcohol Syndrome, presented a preview of *Tools for Success*, a curriculum for professionals in juvenile justice, to a standing-room-only group of participants.

### Wednesday, May 10, 2006—Plenary Sessions

#### Welcome and Introduction

Ammie Akyere Bonsu, MPH, Project Officer, SAMHSA FASD Center for Excellence

Ms. Bonsu welcomed participants to the fourth BFSS meeting and offered greetings on behalf of Mr. Charles Curie, SAMHSA Administrator, and Mr. Dennis O. Romero, Acting Director of the Center for Substance Abuse Prevention (CSAP). Ms. Bonsu thanked the BFSS Planning Committee and staff of the FASD Center for Excellence for their efforts in organizing the meeting.

She noted that the BFSS meeting is a direct response to two of the Center’s congressional mandates: to identify comprehensive systems of care and to provide TA to communities with and without these comprehensive systems. The meeting presents an opportunity to (1) continue to dialog across Federal agencies, States, and local constituency groups and (2) forge partnerships to focus attention on promising interventions for FASD prevention and treatment.

Since the inception of the Center, there has been overwhelmingly positive feedback about the learning opportunities presented by the BFSS meetings.

Ms. Bonsu noted that membership in the National Association of FASD State Coordinators (NAFSC) continues to increase and expressed her appreciation for all associated with the Center, including those working with juvenile justice and the American Indian/Alaska Native/Native



Hawaiian Stakeholders group. She also noted that addressing FASD requires increased awareness, comprehensive systems of care for children and adults with FASD, and the infrastructure to support lasting change.

Ms. Bonsu gave an overview of agenda items and encouraged the participants to support one another and to share innovative strategies.

### **SAMHSA FASD Center for Excellence: Accomplishments Since May 2005 and Future Directions**

**Callie Gass, BA**, Project Director, SAMHSA FASD Center for Excellence

Ms. Gass organized her update of Center activities along the mandates under which the Center was established. The first two mandates she discussed were:

*Provide technical assistance to communities who do not have a comprehensive system of care for such individuals and their families.*

*Identify communities that offer an exemplary comprehensive system of care for such individuals, so that they can provide technical assistance to other communities attempting to set up such a system of care.*

The work accomplished under these mandates has included:

- Providing technical assistance, including establishing and staffing the information resource center (open 5 days a week), providing expert consultation and customized research, conducting site visits, and establishing mentoring relationships.
- Supporting State responses to FASD, including working with 10 States through subcontracts as well as other States.
- Creating FASD responses in Native communities such as convening stakeholder meetings, offering special trainer sessions, providing training and TA to specific tribes, holding a training institute for American Indian professionals, and creating a resource kit for Native communities.
- Working toward building capacity by including the use of field trainers, providing technical assistance and support to subcontractors, and supporting expansion of diagnostic capacity.

Ms. Gass then provided information on work accomplished under the next mandate.

*Provide training to community leaders, mental health and substance abuse professionals, families, law enforcement personnel, judges, health professionals, persons working in financial assistance programs, social service personnel, child welfare professionals, and other service providers on the implications of fetal alcohol syndrome and alcohol-related birth defects, the early identification of, and referral for such conditions.*



Under this mandate, Ms. Gass cited 87 trainings that have been conducted since September 2005; a highly visited, well-respected Web site, which is now available in Spanish; and new materials, reports, and proceedings. New materials include a booklet for siblings and parents of children with an FASD; Tools for Success, a curriculum for training professionals in the juvenile justice system that was developed with the Minnesota Organization on Fetal Alcohol Syndrome; an interactive online course on FASD for professionals, policymakers, parents, and families; and a two-level curriculum for addiction professionals, developed in conjunction with the National Organization on Fetal Alcohol Syndrome (NOFAS), that addresses FASD in the context of treatment. Ms. Gass stressed the critical nature of this mandate and noted that she and the Center had assembled a competent group of trainers with a wide variety of subject matter expertise. She also expressed her desire to develop and provide more advanced training in the future.

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*Ms. Gass cited 87 trainings  
that have been conducted  
since September 2005*

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The final mandates are:

*Study adaptations of innovative clinical interventions and service delivery improvement strategies for children and adults with Fetal Alcohol Syndrome (FAS) or Alcohol-Related Birth Defects (ARBD) and their families.*

*Develop innovative techniques for preventing alcohol use by women in their childbearing years.*

In the area of prevention, the following activities were conducted:

- Completed the third and final pilot of summits for women in recovery from alcohol abuse in Raleigh, NC. Each of the summits featured legislators and triggered FASD policy initiatives in the respective States. A manual on how to plan and host a women's summit is in draft form and will soon be submitted to SAMHSA for approval.
- Supported Circle of Hope, a NOFAS-organized effort, and convened the first meeting of the Circle of Hope in conjunction with the Raleigh women's summit.
- Integrated alcohol screening and interventions into maternity, family planning, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), home visitation, and other programs through subcontracts.
- Integrated contraception assessment and intervention into alcohol treatment for women and programs for women of childbearing age through subcontracts.
- Established four Parent-Child Assistance Programs through subcontracts.

Relative to identifying and treating youth with FASD, the Center has worked toward the following goals, primarily through subcontracts:

- Integrating FASD screening and intervention into juvenile justice and other settings.
- Developing FASD residential treatment that is showing significant improvements in youth.
- Developing FASD interventions and modifications of existing treatments.



Ms. Gass noted that the Center has advanced further in 4 years than initially expected. She expressed her pleasure at the success of the Center and thanked the attendees for their participation and activism.

### Keynote Speaker's Address

**Introduction: Ammie Akyere Bonsu, MPH,** Project Officer, SAMHSA FASD Center for Excellence

Before introducing the keynote address, Ms. Bonsu hosted a tribute to Dr. Faye J. Calhoun. Dr. Calhoun recently retired from her position as deputy director of the National Institute on Alcohol Abuse and Alcoholism (NIAAA) after almost 40 years of Government service. Colleagues and friends gave accolades to and shared fond memories of Dr. Calhoun. Speakers included Ms. Bonsu, Dr. Phillip May, Ms. Doreen May, Ms. L. Diane Casto (on behalf of Dr. H. Eugene Hoyme), and Mr. Rob Wybrecht. On behalf of CSAP Acting Director Mr. Dennis O. Romero, Ms. Bonsu presented Dr. Calhoun with a lifetime achievement award for her dedicated service.

Dr. Calhoun thanked everyone for the unexpected tribute and thanked God for wonderful colleagues and friends and for the strength to keep moving things forward. She noted that the Center and the States deserved a lot of respect for the work they have accomplished.

**Speaker: Faye J. Calhoun, DPA, MS,** Former Deputy Director, NIAAA, National Institutes of Health

Dr. Calhoun noted that FASD history could be separated into two types—(1) research history and (2) administrative/legislative history. Both present challenges:

- FASD surveillance is difficult.
- Research is needed to help affected children and adults.
- There is a lack of sufficient funding.
- FASD provokes stigma.
- The time and talents of those working in FASD are stretched thin.



Dr. Calhoun presented a model for State coordination of FAS. Leading the coordination effort is the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS), which includes participation by the Departments of Education (DOE), Health and Human Services (DHHS), and Justice (DOJ), as well as several DHHS agencies.

In the past 5 years, formal interactions among ICCFAS member organizations have increased dramatically. Dr. Calhoun noted that the model for agencies working together should include collaboration, advice and consultation, cooperation, communication, and sharing of resources.



Dr. Calhoun used a research partnership between NIAAA and the National Institute of Child Health and Human Development (NICHD) as an example of productive collaboration. They are working together on a prenatal alcohol exposure, sudden infant death syndrome (SIDS), and stillbirths study. It is a co-funded, collaborative, multisite, multidisciplinary study with sites in the United States and South Africa. Researchers are looking for lower brainstem abnormalities in brain autopsies of SIDS infants. The lower brainstem controls functions associated with SIDS risk: respiration, arousal, and temperature regulation. Both NIAAA and NICHD have found common ground through this research. In another partnership example, NOFAS collaborated with the Health Resources and Services Administration to write a letter outlining problems caused by alcohol to Congress. This letter led to a 2007 budget resolution in support of funding for FASD.

Dr. Calhoun urged participants to find partners to help further their work, including those who are involved in addressing related disorders, smoking, risky sex, HIV, services for developmental disorders, developmental research, and healthy pregnancies. She encouraged participants to transform agencies, advocates, nonprofits, affected persons, clinicians, researchers, legislators, and policymakers into stakeholders. She also advised them to support stakeholders' concerns (e.g., visibility, reports and publications, services, access to populations, re-election).

Dr. Calhoun stressed the need for participants to post the Surgeon General's Advisory on Alcohol and Pregnancy on any materials or giveaways they produce. The February 21, 2005, advisory warns pregnant women and women who may become pregnant to abstain from alcohol consumption to eliminate the chance of giving birth to a baby with any of the harmful effects of FASD.

Dr. Calhoun stressed the need for all persons working in the field to thoroughly understand and be able to explain problems related to prenatal alcohol exposure and the difficulties in diagnosing FAS and other disorders in the spectrum. Researchers are working to develop tests to identify specific damage. Everyone, particularly legislators, should know that alcohol can damage brain function and development from the earliest stage of embryonic development through adolescence and young adulthood (judgment and cognition). They should also understand the most common problems related to prenatal alcohol exposure and their economic impact. These problems include:

- Mental health problems
- Disrupted school experience
- Trouble with the law
- Confinement
- Inappropriate sexual behavior



- Alcohol and drug problems
- Dependent living
- Problems with employment

Dr. Calhoun encouraged States to develop interagency work groups to focus on education and affected children, justice and delinquency, and prevention of drinking during pregnancy. She closed her address by thanking the attendees for their acceptance, encouragement, and involvement.

### Inspiring Our Work: Sharing Personal Stories

**Moderator: Joyce Jorgenson, BA**, Director, Office of Consumer and Family Affairs, New Hampshire Bureau of Behavioral Health, 2006 BFSS Planning Committee Member

**Speaker: Ginny Wright, BA**, Parent, Hawaii

Ms. Wright greeted participants and thanked them for inspiring her work and giving her the opportunity to inspire theirs. Ms. Wright is the mother of five children, including a 9-year-old daughter, Michelle, who entered her family 6 years ago. A social worker associated with Michelle's adoption told Ms. Wright that Michelle was "a little slow." At 3½, Michelle was not talking and she had just begun to walk.

From her first day with Michelle, Ms. Wright began searching for answers. She had a son with autism and was accustomed to going to multiple doctors and doing research on the Internet. From her research findings, Ms. Wright was sure that her daughter had Williams syndrome, a rare genetic condition that causes developmental and medical problems. She was referred to a mainland clinic, where Michelle was diagnosed with FAS. Ms. Wright was elated after the diagnosis, assuming that she could now seek treatment for Michelle. However, Ms. Wright found no appropriate services for Michelle and little understanding of FAS among professionals. She began reading about FAS and talking to everyone she knew about it. She soon found that parents of children with FAS are the ones with in-depth knowledge, the ones that work to strengthen families, the ones that push policy forward—the real professionals.

Ms. Wright then shared a letter she had written, but never sent, to one of Michelle's teachers, after the teacher had written only two vaguely positive things in Michelle's report card. In the letter, Ms. Wright describes her disappointment in the teacher's inability to see who Michelle really is or understand what she can accomplish with praise, acknowledgement, and progress at her own pace. She encouraged the teacher to look for and see possibilities instead of limitations.



**Speaker: Peggy Combs, Parent, California**

Ms. Peggy Combs expressed her delight at seeing so many people fighting for the same cause. She began telling her story of addiction and parenting a child with FASD. She began drinking and smoking marijuana at 12 years of age. At 24, she learned she was 4 months pregnant. During this period of her life, she worked as a bartender and was using crystal methamphetamine and drinking alcohol. While she tried to stop using and drinking, her fellow bartenders would sneak her drinks. She assumed she would just take care of any problems once the baby was born.



After a full-term pregnancy, Ms. Combs' daughter, Tracy, was born, weighing 5 pounds 9 ounces. Tracy was late in meeting all developmental milestones. When Tracy was 2, a new doctor suggested that she could have FAS.

Initially, Ms. Combs was too busy drinking and using drugs to be an advocate for Tracy. When Tracy began school, she was put into a gated special education class. Ms. Combs felt too guilty to complain.

When Tracy was 13, Child Protective Services (CPS) took her away from her mother. Ms. Combs was able to regain custody but lost Tracy again after only 3 months. At that point, Ms. Combs knew she wanted her daughter back even more than she wanted drugs and alcohol. She was able to get sober and regain custody of Tracy.

Ms. Combs found stories that were similar to her own on FASlink, the Fetal Alcohol Disorders Society Web site. Through the support of those on the listserv and an understanding of secondary disabilities associated with FASD, she and Tracy began making positive changes in their lives. She grappled with grief, guilt, judgment, and hatred, but she found strength and acceptance from other birth mothers.

She now realizes that success is not about money or an advanced education but instead what a person has on the inside. She feels success in knowing that Tracy is happy, has many friends, and has never drank or taken drugs.

**Speaker: Tracy Combs, Individual with an FASD, California**

Ms. Tracy Combs is 22 years old and lives with her mother. She shared photographs and stories about her life with the participants. Ms. Combs has a dog and a cat, works out at a gym, and goes to the library. She likes to view stamps at stamp class, works at a thrift store hanging clothes, and will soon graduate from high school. She used to work at Sea World and hopes to work with animals again. She has a boyfriend named Jason, and they like to dance and go to hockey games. Ms. Combs plans to get married when she is 25. She likes CDs and her Hello Kitty pillow, and she once met Britney Spears. She does not know how to read.



## Using the State Epidemiology Workgroup to Change Policy and Drive Funding

**Moderator: Larry Burd, PhD**, Director, North Dakota School of Medicine and Health Sciences; Acting Co-Chair, FASD Center for Excellence Steering Committee

**Speaker: Ammie Akyere Bonsu, MPH**, Project Officer, SAMHSA FASD Center for Excellence (speaking on behalf of **Mike Lowther, MA**, Acting Director, Division of Knowledge Application and Systems Improvement, CSAP/SAMHSA)

SAMHSA's vision is a life in the community for everyone, and its mission is to build resilience and facilitate recovery for people with or at risk for substance abuse and mental illness. It is comprised of three centers—CSAP, the Center for Substance Abuse Treatment (CSAT), and the Center for Mental Health Services (CMHS). SAMHSA builds its programs around three key principles: accountability, capacity, and effectiveness (ACE).

Ms. Bonsu noted that prevention is vital to supporting quality of life, including a healthy, drug-free, crime-free environment and access to needed services. Prevention requires long-term changes in communities. Communities need to work to reduce the impact of FASD, and State and local agencies need to collaborate on FASD-related issues. SAMHSA has begun developing State Prevention Systems comprised of a prevention system leadership group (i.e., top-level decisionmakers) and workgroups from various agencies (e.g., epidemiology, capacity, strategies, planning, and evaluation). Ms. Bonsu noted that SAMHSA has provided funding for every State to have an epidemiology work group to discuss and monitor emerging trends in alcohol and substance abuse and to pinpoint areas of increased activity.

SAMHSA's Strategic Prevention Framework (SPF) is a community development process that empowers communities to identify problems, available resources, potential solutions, and actions and to determine the effectiveness of the actions taken. In closing, Ms. Bonsu encouraged the participants to implement SPF processes and to raise the visibility of FASD in the community.

**Speaker: Cheryl Lauber, MSN, DPA, RN**, State FAS Coordinator, Michigan Department of Community Health, NAFSC Member

Dr. Lauber discussed the new Detroit FAS Prevention Project. She acknowledged the inspiration and assistance of Barbara and Rob Wybrecht and others in the field.

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a surveillance project of the Centers for Disease Control and Prevention (CDC) and State health departments. Data from the 2002 survey indicated that 52 percent of women drank prior to pregnancy, 64.9 percent of black and 37.7 percent of white pregnancies were unintended, and 4.4 percent of women drank during pregnancy. In looking at data from substance abuse centers in Detroit and Wayne County, Dr. Lauber found that substance abuse was more common in older white women (i.e., age 30 to 44) and that 12 percent of the women entering substance abuse treatment were pregnant at the time of admission. She noted that it is relatively common for pregnant women in substance abuse



treatment to have children born with birth defects. For example, data from 2000 to 2003 showed that children born to alcohol users in substance abuse treatment in Detroit were almost four times more likely to give birth to a child with birth defects than women in the general population (27 percent versus 7 percent). The defects reported in the Michigan Birth Defects Registry included FAS and microcephaly.

Dr. Lauber noted that outreach is the most important component of Detroit's prevention strategy, including:

- A three-panel presentation board with information about FASD and pictures
- Simulator infant dolls with FAS facial characteristics
- Slide shows for various audiences, from school children to medical providers
- Literature and other giveaways related to FASD (e.g., brochures, booklets, fact sheets, bookmarks, posters)

Dr. Lauber and her colleagues have found one-on-one recruitment to work best and mailings to be least effective. Other methods include flyers, phone calls, and referrals. The current goals for the program are:

- To recruit and screen 1,000 women of childbearing age in the city of Detroit
- To enroll 100 women in the Personal CHOICES intervention
- To screen 25 women through the self-guided change intervention

The outcome objectives are:

- To identify women drinking eight or more drinks per week and/or four or more drinks in a day
- To identify women not using contraceptives
- To give FASD information to all at-risk women
- To give feedback on at-risk behavior
- To provide birth control information

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A grant requires the project to link women to services at an FAS diagnostic center that includes a genetics clinic and provides FAS evaluations. In closing, Dr. Lauber described Michigan's FASD system, which is organized under the FASD State Coordinator and includes:

- State Task Force
- Program Advisory Group
- Community prevention grants



- Pilot screening projects with foster care (3)
- Diagnostic centers (6)
- Community linkage to service grants
- Local parent support groups

**Speaker: Pamela Gillen, ND, RN, CACII**, Project Coordinator, University of Colorado Health Sciences Center; FASD Center for Excellence Steering Committee Member and Science to Service Chairperson; FASD Center for Excellence Field Trainer; NAFSC Member

Ms. Gillen discussed an FAS prevention project in Colorado, one of eight States to be funded by a CDC 5-year cooperative agreement. The two partners in the Colorado project are the Colorado Department of Public Health and Environment and the University of Colorado Health Sciences Center. To meet the various project goals, staff:

- Have adapted and simplified the Colorado FASSNet System (now called FASLink) to identify cases and generate population-based estimates of the prevalence of FAS.
- Use FASLink sources and referrals from social services, treatment, and health programs.
- Address barriers to accessing appropriate services and provide assistance in referring children and families to services (e.g., project staff have trained mental health services staff in all eight counties).
- Train providers and professionals to identify children with prenatal alcohol exposure and refer them to appropriate services.

Expected outcomes for the stepped-care and community-level intervention components of the project include (1) a reduction in alcohol use rates among childbearing women, (2) an increase in contraceptive measures, (3) an increase in self-efficacy and improvement in quality of life indices, and (4) a decrease in unplanned pregnancies.

Recruitment for the stepped-care intervention includes use of referrals, incentives (e.g., Target or grocery store gift cards), brochures, and posters. Recruitment for the community-level intervention includes use of radio spots, clinic videos, TV and bus ads, newspaper articles and press releases, online information, flyers, brochures, and posters.

Ms. Gillen shared some of the project's intervention and media campaign messages, including:

*If you party, party wise.*

*Missed a period/Don't drink period.*

*Pregnancy—NOT NOW! If you drink don't get pregnant. Drinking alcohol while pregnant is the leading known cause of preventable mental retardation and birth defects.*



Intervention activities include group intervention, a brief intervention, short-term case management, specialized intensive case management, and a self-guided phone intervention program. Interventions target women at high risk for consuming alcohol during pregnancy. One target group is young women who exhibit binge drinking behavior. A personal skills component provides ongoing sessions for 3 to 6 months to help women develop skills needed to achieve goals around alcohol and contraceptive use. A personal support component provides long-term case management (up to 3 years) for pregnant clients or those with a significant alcohol abuse history.

Ms. Gillen closed by describing the evaluation goals, process, and outcomes for the project. The outcomes will include the following:

- The impact of intervention on the woman's knowledge and attitudes about alcohol use during pregnancy or when at risk for pregnancy.
- Changes in the amount and pattern of alcohol use before and after the intervention.
- Risk for an alcohol-exposed pregnancy (contraceptive use).
- Types of services accessed from other community service agencies to support and maintain behavior change.
- Women's reports of services needed that were unavailable or inaccessible to them.
- Women's reports of increased self-efficacy.
- Women's reports of improved life and health domains.

### Questions and Comments

A participant asked Dr. Lauber if she had considered screening all of the children of women in substance abuse programs. Dr. Lauber noted that it was a great idea, but that after screening, there were problems getting children into the system. She commented that they were also interested in screening children in foster care.

One State is trying to get geneticists to use a checklist to gather information, including a child's birth weight, the mother's prenatal alcohol use, and any developmental delays or behaviors for concern. Accessing information from chart records can be both helpful and frustrating. Staff in Michigan have found very few records with FASD-related diagnoses. Staff from Colorado stressed the need to train doctors in adequate documentation.

### Reaching Women at High Risk—A State System Approach to Changing Behavior

**Moderator: Deborah Cohen, PhD**, Director, Office of Prevention of Mental Retardation and Developmental Disabilities, New Jersey Department of Human Services; FASD Center for Excellence Steering Committee Member



## Reaching Women At High Risk—A State System Approach to Changing Behavior

**Speaker: Therese Grant, PhD**, Research Assistant Professor, Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine; Director, Fetal Alcohol and Drug Unit; Director, Washington State Parent-Child Assistance Program

Dr. Grant expressed her pleasure at presenting to the group. She noted that maternal alcohol and drug use puts children at risk because of (1) possible effects of prenatal exposure on the child's health, (2) the likelihood of a compromised home environment, and (3) the likelihood that the mothers will have more exposed, affected children. These problems are costly to society and are completely preventable.

The Washington State Parent-Child Assistance Program (PCAP) is an intensive, 3-year home visitation model with intervention for high-risk alcohol and/or drug abusing mothers. Dr. Grant noted that when the program began enrolling participants, many social service agencies had case managers, but no one communicated, made a plan, and followed through. There was also no coordination with other systems/agencies to avoid duplication of efforts. She gave a brief history of PCAP, which has been replicated or adapted in seven States and Canada.

The primary goal of PCAP is to prevent future births of alcohol- and drug-exposed children through interventions with:

- Mothers who drink heavily during pregnancy, to prevent future alcohol-exposed births
- Mothers who have FASD, to prevent secondary disabilities and alcohol-exposed births
- Babies who have FASD, to prevent secondary disabilities

The well-trained and closely monitored advocates/case managers used with this model have experienced some of the same types of adverse life circumstances as the clients and have subsequently made positive changes in their lives. They serve as positive role models and offer clients hope and motivation from a realistic perspective. The maximum caseload recommendation for advocates/case managers is 15 active client families. They are responsible for:

- Connecting a client's service providers with each other to facilitate development of an effective plan.
- Linking clients with appropriate and available community services.
- Providing advocacy for all family members as needed, including work with community providers, alcohol and drug treatment, probation, CPS, mental health treatment, schools, health care, job training, and family planning.

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Dr. Grant stressed that many mothers in PCAP were the abused, neglected children of 10 to 15 years ago. PCAP engages these mothers and their babies together to break the continuum of



intergenerational deprivation. In reviewing enrollment characteristics, Dr. Grant noted that participants had high incidences of being incarcerated, being raised outside of their biologic parent's care, and running away from home. Results for the program were discussed according to treatment and abstinence, family planning, preventing future exposed births, cost savings, child custody, and income. The program has high followup and completion rates, in part because it does not kick women out. Advocates/case managers determine how to work with and support each woman and her family.

Dr. Grant noted that good things happen when communities implement effective programs and States implement strong policy. From 1991 to 2003, Washington's Division of Alcohol and Substance Abuse increased treatment beds for women from 55 to 155. She encouraged participants to work closely with legislators, specifically to:

- Find a legislative champion
- Know your statistics and build your case with evidence-based results
- Keep it simple
- Rally your supporters
- Build coalitions
- Emphasize program cost savings

She gave participants community-, county-, and State-level considerations for replicating the PCAP program. Community-level considerations include facilities, staffing, and evaluation. County-level considerations include varied child welfare policies, attitudes about substance-abusing mothers, and any sanctions that could be imposed. At the State level, the primary consideration is the presence of a supportive infrastructure, which is essential.

In closing, Dr. Grant noted that the program's biggest ongoing challenge was maternal alcohol use during pregnancy and the widespread lack of knowledge among individuals and agencies about its dangers.

### **Reducing Prenatal Alcohol Use: Effective Identification**

**Speaker: Grace Chang, MD, MPH**, Associate Professor of Psychiatry, Harvard Medical School and Brigham and Women's Hospital

Dr. Chang acknowledged NIAAA and the Office of Research on Women's Health, her co-investigators, and research assistants. She began with the Surgeon General's 2005 advisory on alcohol use in pregnancy and data on the prevalence of drinking during pregnancy. The advisory states:

- No amount of prenatal alcohol is safe.
- Alcohol can damage a fetus at any stage of pregnancy.



- Cognitive deficits and behavioral problems resulting from prenatal alcohol exposure are lifelong.
- Alcohol-related birth defects are entirely preventable.

She noted that providers do not have accurate pictures of who drinks when pregnant. According to PRAMS data, those identified with the highest prevalence of alcohol use are non-Hispanic women over 35 with high school educations and higher incomes. Binge drinkers tend to be younger, single, white, cigarette-smoking women who also use illicit drugs.

Dr. Chang then described key aspects of FAS, alcohol-related neurodevelopmental disorder (ARND), and ARBD, noting that ARND was 10 times more prevalent than FAS. She went on to present data to counter the “Just one drink won’t hurt” attitude toward alcohol consumption while pregnant. There is growing evidence that prenatal alcohol consumption at levels of less than one drink per day can adversely affect fetal growth and development even in late pregnancy. Any prenatal alcohol exposure increases by 3.2 times the risk of children having delinquent behavior scores in the clinically significant range. The American Academy of Pediatrics, American College of Obstetricians and Gynecologists, United States Surgeon General, and Secretary of Health and Human Services all recommend abstinence from alcohol to preconceptional and pregnant women.

Dr. Chang noted that increased screening for alcohol use among women who are pregnant—or may become pregnant—is urgently needed. She discussed the need to find a balance between sensitivity and specificity in a screening instrument. Sensitivity is the probability that a person who should test positive, does so. Specificity is the probability that a person who should test negative, does so. Between having more false positives or false negatives, she noted that the preference would be for more false positives. A positive screen is neither an alcoholism diagnosis nor an indictment, just a signal for discussion.

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*Increased screening for alcohol use among women who are pregnant—or may become pregnant—is urgently needed*

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Dr. Chang went on to discuss the T-ACE, a four-item screening instrument based on the CAGE and developed by Dr. R.J. Sokol that appears to be effective in screening for alcohol use in pregnant women. It reflects a pattern of use and has been validated in diverse patient populations. The T-ACE questions are as follows:

- T How many drinks does it take to make you feel high (effects)?
- A Have people ever annoyed you by criticizing your drinking?
- C Have you ever felt you ought to cut down on your drinking?
- E Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover?



The “T” question is given two points for a report of more than two drinks. The other questions get one point for each “yes” reply. The T-ACE is positive with a score of two or more. A positive T-ACE is an opportunity for discussion, assessment, and brief intervention. Dr. Chang noted that taking advantage of these opportunities is highly therapeutic and effective in reducing drinking and closed with a recommendation that all pregnant women be screened.

### Questions and Comments

A participant asked Dr. Chang to comment on how to reach middle-class white women and their providers. Dr. Chang noted that providers needed to be educated; many are not aware of their patients’ drinking or possibly even the problems associated with prenatal drinking. Dr. Chang noted that a recent review of prenatal medical textbooks found many with no mention of the risks associated with prenatal drinking. In response to a questions about using T-ACE on women who are not pregnant, Dr. Chang noted that a study is beginning—using T-ACE—on women with issues exacerbated by drinking.

A participant mentioned a physician’s quote in People magazine suggesting that it is fine to drink up to a pint of beer a day while pregnant. Another participant commented that there are nurses who do not believe that FASD exists, as well as women who say they drank through their pregnancies and their children are fine.

### Thursday, May 11, 2006—Plenary Sessions

#### Evidence-Based Interventions for Children With an FASD

**Moderator:** Julie Gelo, Parent, Family Advocate/Trainer/Consultant, and Executive Director, National Organization on Fetal Alcohol Syndrome Washington State; University of Washington FAS Diagnostic and Prevention Network; FASD Center for Excellence Steering Committee Member; 2006 BFSS Planning Committee Member

#### Fetal Alcohol Syndrome: Socio-Cognitive Habilitation

**Speaker:** Claire D. Coles, PhD, Director, Maternal Substance Abuse and Child Development Project, and Professor, Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine; Director, Fetal Alcohol Center, Marcus Institute

Dr. Coles greeted the group, thanked them for their enthusiastic welcome, and began to discuss The Marcus Intervention Project, which is funded by CDC. Her project, based in Atlanta, is one of five intervention sites focusing on FASD. The major goals of the project, developed to meet the requirements of the request for grant application, are as follows:

- Support, educate, and empower caregivers.
- Achieve learning readiness.
- Identify a method to improve mathematical achievement by compensating for core deficits.



The goal to focus on caregivers was chosen to respect caregivers as the principle agents of change and to recognize the stress associated with caregiving and the limited resources and support available to caregivers. Dr. Coles noted that most of the alcohol-affected children that come to the clinic also have problematic environmental histories and arousal regulation problems. To get the children ready to learn, their social/emotional, medical, and/or environmental problems must first be treated.

Finding appropriate therapeutic care for the child and obtaining appropriate parental support services are included under case management. The psychiatric evaluation and assessment determines the need for behavioral/emotional therapy or any appropriate medications. Project staff also work with clients to provide supports that encourage participation such as transportation, babysitting, flexible work hours, and reimbursement for gas.

Dr. Coles noted that math is often a marker of underlying “core deficits” that interfere with learning. These core deficits can impact motor skills, arousal regulation, visual/spatial skills, and learning. Teaching methods can address these problems.

Dr. Coles discussed the target population for the study: children between the ages of 3 and 9 with a diagnosis of FAS or partial fetal alcohol syndrome (pFAS) that have been in a consistent placement for 6 months and have projected stability over the next 6 months. Recruitment sources included the existing client base, new clients requesting clinical services, and community referrals. The intervention study design includes:

- Pretesting to identify deficits in basic learning skills and tailor interventions to each child’s gaps in knowledge. Teaching strategies were available by age in each skill category.
- Caregiver advocacy training to provide parents and other caregivers education and/or training on the following topics:
  - FAS and pFAS
  - Communicating with pertinent professionals regarding the child’s needs and assisting with goal planning for the child
  - The child’s rights within the educational system
  - Educational, political, social, and legal advocacy
- Learning readiness evaluation, including parent education about FAS, case/social service management, psychiatric evaluation/medication management, neurodevelopmental evaluation, educational management, and behavioral regulation training. As part of behavioral regulation training, parents learn:
  - What behavioral regulation is
  - What social learning principles are and how to apply them in everyday life



- Strategies to modify the child's level of arousal
  - Strategies to modify the child's environment to prevent problematic situations
  - How to get improved compliance from the child
- Math intervention, which is given to half the sample, with group assignment determined by randomly drawing names after the second group session. Strategies include an active learning model (plan-do-review) that was adapted for 3- to 5-year olds from a learning program developed in Michigan, visual materials and aids to teach math, and individualized strategies based on cognitive and math development.
  - Eight-week and 6-month posttesting, which measured outcomes for the caregivers and the students. Caregivers were measured on satisfaction, treatment and FAS knowledge, compliance, family functioning, and behavioral functioning. The students were measured on various math-related outcomes and number writing skills.

Dr. Coles shared a sample curriculum page, supports for various deficits, and a sample parent handout. She noted that the intervention's success was dependent upon the parent's willingness to work with the child on a daily basis. She noted that project staff were lucky to have a dedicated special educator working with them. The special educator was available to, among other things, consult with parents about schools and concerns, observe the child's learning/interaction style during pretesting, and visit the teachers of the test-group children to discuss how best to teach children with FAS.

Dr. Coles noted that the results from the intervention have been promising. She closed with a slide showing the marked improvement in one subject's handwriting at the first and second posttests.

### **Fetal Alcohol Spectrum Disorders: Meeting the Challenge of Intervention—The Families Moving Forward Program**

**Speaker: Heather Carmichael Olson, PhD**, Senior Lecturer, Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine; Psychologist, Children's Hospital and Medical Center and University of Washington FAS Diagnostic Clinic

Dr. Olson shared information on the current status of FASD intervention and research, with suggestions for services communities and States may want to build. She also reviewed initial research evidence on the Families Moving Forward (FMF) program.

She noted that researchers are looking at various ways to help children with FASD learn and function better (e.g., tools and intervention models, nutritional supplements). She described continuums of FASD services that need to be built. Under the initial services continuum, she included screening and diagnostic systems, effective linkage methods, and community awareness. Under the continuing services continuum, she included early intervention, parent support networks, specialized training and consultations within systems, specialized mental health



services, child-focused treatment, and parent support and education.

The FMF program is a newly created, flexible, practical model that responds to the individual needs of a high-priority subset of families raising preschool and school-aged children with FASD. The FMF program assumes that parents are the main advocates for those with FASD and that they need assistance. The program also helps to operationalize basic treatment processes and techniques for FASD intervention, providing content for professional training programs.

For the CDC-funded FMF program, Dr. Olson's group selected school-aged children with FASD and clinically concerning externalizing behavior problems—a group at highest risk for secondary disabilities. A practical intervention was needed for children who commonly show attention deficits, aggression, oppositional acts, and social problems. These behavior problems are thought to be partly due to underlying brain-based “primary disabilities.” They affect the acquisition of new knowledge and skills, behavior regulation, and sensory sensitivities and sensory integration. The proposed solution was to create a risk/protective factors model based on existing child treatment literature (i.e., different populations with similarities) and wisdom on FASD.

Dr. Olson outlined some protective factors against secondary disabilities. These include the following:

- Early diagnosis
- A stable caregiving environment
- Non-substance-abusing parents or guardians
- Safety from violence
- Social services advocates

The FMF intervention is done in a behavioral consultation format. It includes collaborative consultation with parents and is focused on building problem-solving skills and stress management. It has been found to improve outcomes for parents, siblings, and children with conditions such as traumatic brain injury and developmental disabilities.

Dr. Olson noted that when parents raising children with FASD were asked what they needed to help support their child's learning and care, they wished for:

- More time with professionals who can explain useful learning and behavior strategies
- Time to process issues, for self care, and to access resources
- Parent-to-parent support

Taking these needs into consideration, the FMF intervention was designed as a home-based behavioral consultation intervention for families raising school-aged children with a diagnosis of an FASD and behavior problems. It focuses in part on treatment processes that may lead to



improvements in parenting attitudes and childrearing practices. The model included 9 to 11 months of low intensity, sustained intervention, with consultation services provided by a specially trained behavioral specialist, supported by a clinical supervisor and consultants on treatment processes and special topics.

Dr. Olson shared the specifics of the randomized control trial and sample characteristics of the children and families. The largest portion of caregivers was adoptive parents/legal guardians. She noted that 94 percent of the parents/caregivers reported clinical levels of child-related stress. The children in the study had very significant behavior problems, including externalizing problems, internalizing problems, aggression, attention problems, and social problems. The children had relatively average IQs but tested high for psychiatric diagnoses such as attention deficit hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD), and over half of them had borderline or poor memories. The childrens' learning profiles showed variable and significant neurodevelopmental disabilities.

Dr. Olson cautioned participants that interpretation of the research from the FMF program was just beginning, but she noted that the program was a promising practice and that the training and intervention model would be of great use in communities with lower standards of care. She then shared some preliminary clinical and parent behavioral outcomes. Some of the clinical outcomes included:

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*94 percent of  
the parents/caregivers  
reported clinical levels of  
child-related stress*

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- Treatment compliance of 92 percent with the basic intervention.
- FMF treatment specialists saw treatment as feasible and acceptable.
- The training program was feasible and can be adapted for other providers.
- Service costs are within viable funding limits.

Intervention parents self-reported that they were becoming more consistent and less harsh with their discipline and were more often assessing the circumstances, precursors, and functions of problem behaviors. The findings also showed that disruptive behavior improved and parents felt more effective; however, parents' feelings of stress did not diminish.

The next steps for the FMF program include writing up the findings, conducting ongoing research aimed at transitioning the program into communities and varied settings, refining the program and adapting it to other uses, and developing models of early intervention and child-focused treatment based on the FMF program.

### Questions and Comments

A parent advocate expressed frustration about the slow rate at which support and services reach children with FASD and their parents. In response to questions about staffing, Dr. Coles noted



that her behavioral technicians were mostly graduate students hired from universities and that her intervention is moving away from PhD support specialists and toward MSWs and possibly paraprofessionals. In response to a question about the cost of the Marcus intervention, Dr. Coles responded that it is significant and takes time. Dr. Coles also noted that the math intervention curriculum would eventually be put online.

## Updating State Goals and Objectives

**Overview:** Callie Gass, Project Director, SAMHSA FASD Center for Excellence

Representatives from each State met to complete a State Team Meeting Worksheet about the State's plans and a questionnaire about State activities. FASD Center staff provided participants with their 2005 State plans to use as a resource. Items on the worksheet included the following:



1. Review the 5-year goals given in 2005 for your State in terms of building a State system to address FASD. Are your goals the same for 2006? If not, what is the new goal? Why has it changed?
2. Have you completed the key tasks needed to accomplish your State's goal over the past year? If the goal changed for 2006, what are the key tasks needed to accomplish the new goal?
3. List some of the major barriers to achieving your State's goal over the past year. If the goal changed for 2006, what are some of the anticipated barriers to achieving the new goal?
4. What are some strategies or steps you have used or could use to overcome these barriers?
5. List three action steps toward developing a State system that you would like to accomplish within the next year.

Participants gave their completed worksheets and questionnaires to Center staff to copy and mail to them after the meeting.

## FASD Efforts in Canada: Learning From Our Neighbors

**Moderator:** Dan Dubovsky, MSW, FASD Specialist, SAMHSA FASD Center for Excellence

**Speaker:** Nadine S. Huggins, BA, MPPPA, Manager, FASD Strategic Programming Unit, First Nations and Inuit Health Branch of Health Canada

Ms. Huggins stated that Canada's population is approximately 32.5 million. In the 2001 census, 976,000 reported themselves as aboriginals (4 years earlier, that number was 799,000). There are 626 First Nations communities and 53 Inuit communities. These communities typically have less than 1,000 people and have large percentages of people under 20 years old.



She briefly reviewed highlights in the Government of Canada's commitment to FASD, including the 2005 Blueprint on Aboriginal Health, which provides a 10-year transformative plan and will include a roadmap to guide federal action and collaboration in closing the gap in health outcomes between Aboriginal peoples and Canadians as a whole.

She noted that the bulk of FASD initiative dollars were committed to the First Nations and Inuit peoples, though FASD was not more statistically prevalent in these groups.

Ms. Huggins shared Health Canada's mission and vision:

*Health Canada is the federal department responsible for helping the people of Canada maintain and improve their health.*

*Health Canada is committed to improving the lives of all Canada's people and to making Canada's population among the healthiest in the world as measured by longevity, lifestyle, and effective use of the public health care system.*

In support of this mission and vision, Ms. Huggins' branch of Health Canada works with provincial and territorial governments to provide national leadership to develop health policy, enforce health regulations, promote disease prevention, and enhance healthy living for all Canadians. Their specific mandates include the following:

- To improve health outcomes of First Nations and Inuit
- To ensure availability and accessibility of quality health service
- To support greater control of the health system by First Nations and Inuit

She then discussed her branch's FASD program, noting that the budget has grown from \$1 million to a respectful \$16.7 million. She thanked the Center for its support and constant assistance. The goals of the program are to (1) reduce the

incidence of FASD births and (2) to lessen the impact of FASD on the quality of life of the affected children and their families. Programming was developed that is community-based and community "paced," with delivery models that can be adopted or adapted by the community, and performance measurement and evaluation for community benefit. The program components include the following:

- Capacity building with asset mapping; awareness, education, and training; and assessment of community readiness to deal with FASD
- Prevention with mentoring and targeted interventions
- Intervention with multidisciplinary teams and parent and family support



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*The budget has grown from  
\$1 million to a respectful  
\$16.7 million*

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Ms. Huggins spent some time discussing asset mapping, an approach to community planning that encourages communities to mobilize their strengths to build support around issues of concern in their community. Community assets can be people; programs, services, or organizations; professional groups; physical things (e.g., buildings, land, water, sacred areas); or economic assets. Program staff work with community members to determine their assets, usually using a 2-day process. Once assets are determined, they are built into the community's action plan.

The mentoring program is structured after the PCAP model and consists of 12 programs already delivering services. It includes:

- A 3-year home visitation program for high-risk women
- Services grounded in Native culture and values

With respect to performance measurement and evaluation, Ms. Huggins noted that they were encouraging communities to partner in evaluation and to determine practical application of the knowledge gathered. She also shared information on the number of asset mapping projects and mentoring programs completed by region.

Ms. Huggins shared future plans, noting that the branch intended to:

- Build the evidence base for decisionmaking
- Support building community capacity
- Strengthen public and professional awareness, knowledge, and skills development
- Support a multi-year research strategy to better understand FASD
- Anchor FASD in broader Native programs
- Strengthen federal/provincial/territorial partnerships
- Collaborate with other federal departments and sectors

In closing, Ms. Huggins noted her fortunate success at building trusting relationships and getting communities to embrace the program.

**Speaker: Sterling Clarren, MD, FAAP**, Chief Executive Officer and Scientific Director, Canada Northwest FASD Research Network; Clinical Professor of Pediatrics, University of British Columbia

Dr. Clarren discussed his work with the Canada Northwest Research Network. He noted that a group of ministers had been meeting to discuss FASD since the 1990's, and in 2003 the research network was formed.



The Phase I goals of this group include (1) initiating a scan of all FASD work in Canada Northwest, (2) organizing the work into units for networking that would include present data sets and determination of future research directions, and (3) proposing a structure for active networking to begin in Phase II.

The group found that there were approximately 150 small, active FASD-related projects in Canada Northwest that included prevention, surveillance, diagnostics and mechanisms, and treatments and interventions. Forums were held to prioritize the goal-focused work. There was broad, supportive participation at each forum. Information was gathered from forum attendees, and the following points were distilled:

- All clinics across the region were doing approximately 1,100 assessments a year.
- Teams included a wide variety of professionals.
- Most evaluations were performed on children 3 to 12 years of age.
- Most clinics used the 4-digit diagnostic system that had not been locally modified.

The group decided that despite significant challenges, consistent, combined data from all of the clinics would be an invaluable source for: first prevalence figures for FASD in Canada; identification of areas of inadequate clinical capacity; determination of the unmet medical, mental health, and educational needs of patients; and access to populations for clinical trials with new and innovative approaches to intervention. It was determined that the group would evaluate the data along the following contexts: cultural diversity, gender, community, geography, and priority for improved outcomes.

Dr. Clarren noted that a large quantity of prevention materials was being used, but that none had been assessed for effectiveness. It was calculated that approximately 17,000 different pamphlets, posters, giveaways, video tapes, and other materials had been produced.

After the forums were held, network action teams were formed to look into FASD diagnosis, intervention, and prevention. Network integrating teams were formed to provide information, guidance, and direction to the action teams. Large agencies were selected to lead the combined effort. These were organizations:

- With an infrastructure in place for negotiating contracts, accepting funds, and managing budgets
- Interested in FASD with a track record of capability in research
- With personnel in place who could provide the support needed for the project
- Distributed as widely as possible throughout Canada Northwest

In closing, Dr. Clarren noted that the effort would be challenging and fascinating and hopefully would advance the field of FAS.



**Speaker: Eunice Bergstrom, BA**, Project Developer, Supported Housing for Persons With FASD, FASD Network of Saskatchewan

The FASD Support Network of Saskatchewan (the Network) is a non-profit organization led by a parent advisory board. It has long recognized housing as a critical factor in the lives of adults with FASD. Ms. Bergstrom discussed a collaboration between the Network and the Saskatoon FASD Inter-agency Committee to develop an application for funding to conduct a feasibility study in Saskatoon. The intention was that the feasibility study would lead to supported housing for persons with FASD.

A steering committee provided structure for the project and undertook the following activities:

- Reviewing the literature to develop a description of the characteristics of adults with FASD, how these affect homelessness, and efforts in other locations to alleviate homelessness.
- Establishing the vision, guiding principles, and goals for the project.
- Raising awareness of the project and its goals through networking with others in the community and developing community partnerships.
- Providing information and training to others in the community.
- Identifying the range of needs that exist for persons with FASD.
- Compiling an inventory of the community supports and existing resources.
- Identifying gaps and proposing ways to fill those gaps.

Based on these activities, four understandings emerged.

1. The presence of ongoing support with some accessibility on a 24/7 basis will have the greatest effect on stability in the lives of individuals with FASD and their quality of life.
2. Concentrating on the support aspect, rather than building homes, holds the best promise for supporting larger numbers of persons with FASD. It develops a process that is flexible and appropriate and that holds promise for meeting the needs of all older youth/adults with FASD.
3. There is a continuum of housing options in Saskatoon, ranging from privately owned options to various levels of social and supported housing. The preference is to work with others who have an expertise in providing housing, and put the energy of the project into devising the ongoing support system that is currently not available.
4. Working with existing organizations and resources is seen as optimal, adds efficiency and strength, and allows for a modest design of the project. That means linking with other agencies and other supported employment initiatives.

The goal of the Supported Housing Project is to assist each individual to attain their unique balance point of maximum independence (or interdependence) and required support.



Through a feasibility study process, it became apparent that the development of a foundation system of ongoing supports, that could be accessed by persons with cognitive disabilities, irrespective of where they live, is the vital ingredient to maintaining housing and stabilizing their lives. This foundation creates the potential to meet the support needs of all persons with cognitive disabilities along the continuum of very minor to extreme needs and unites housing with ongoing individualized support.

The acquired understandings, combined with the results of the feasibility study, led to the development of four models that have provisions for ongoing individualized supports. Providers from two thriving projects for persons with FASD in Canada participated extensively in the development of the four models.

Since the first model, the Foundation Model, has the potential to reach a wide number of persons with FASD, the steering committee decided that it should take priority. This model could expand, as needed, to incorporate the other models.

A partnership between the Network and the Saskatoon Crisis Management formed and together they developed a proposal for project based on the Foundational Model and based on 3-year funding for three additional staff. These staff would continue to develop the capacity of the community to respond effectively and appropriately to housing and support needs of youth and adults with FASD. At the same time, they would provide one-to-one support and act as coordinators of support. It is anticipated that in the first year each staff would have about five persons on their case load.

Important aspects of the project are the provision of supports for persons with FASD and for the staff. This is reflected in the recognition of the frequent need for access to 24/7 support for persons with FASD and for training, adequate salary, and supportive work environment for the staff. The second model then, is an important adjunct to the Foundation Model. If resources are available, the project partners will explore the possibility of a resource centre and development of a roster of advocates and mentors.

Government has not yet provided funding so the project partners have applied for grants from various sources. The need to begin providing supports to persons with FASD outweighs the reluctance to begin piecing together the project with short-term funding. The instability in funding means that Saskatoon Crisis Management can not commit to being the major partner and delivery structure. As a consequence, the support offered to persons with FASD will be less comprehensive, and is unlikely to include access to 24-hour support. The concern about offering services that might cease if avenues for funding are exhausted is partially alleviated by the implementation of the Cognitive Disability Strategy (CDS). Although limited, CDS may offer a means of some ongoing support. However, the benefits from CDS, at this time, are financial only, so they do not include identifying and accessing supports and services, and pertain only to an unmet need.



Goals for the future of the project include implementing services to the extent possible using available grant funds, establishing ongoing funding, providing training, and fostering partnerships. The proposed plan is well-researched, comprehensive, and respectful of the needs of persons with FASD as well as their service providers. It is ambitious and comes with what might be a high price tag. These support costs in comparison to the default costs of hospital stays, corrections costs, or holding a youth in custody are markedly less expensive in economic terms. However, what should be most compelling is the consideration of the human costs, and loss of potential that occurs when the needs of those with FASD are ignored.

## Questions and Comments

In response to a question, Ms. Bergstrom noted that she was working to build support among judges. Dr. Clarren noted differences in attitudes between Canadian and American researchers. He noted that anyone who brought data to their Canada Northwest repository could also take data out. In response to a question about her mentoring program and community readiness, Ms. Huggins noted that without leadership buy-in or community support, the work would not succeed. She also noted that asset mapping is helpful in determining what would work best in an area and in fostering as much community involvement as possible. She also mentioned that some communities need FASD 101 before embarking on the mapping process. Her group lets communities set their own pace.

Dr. Clarren noted that he's seen a "tipping point" in Canada regarding FASD. Some time ago, there was only one person in each province providing FAS diagnostic services. Parents began advocating for their children and got the attention of the government, and now FASD is an important part of the Canadian health agenda. He hoped that the United States would have a similar experience. He also reminded participants that they were all important agents of change.



## Wrap-Up and Closing Remarks

**Callie Gass**, Project Director, SAMHSA FASD Center for Excellence

Ms. Gass thanked everyone for a wonderful meeting and congratulated the planning committee for its hard work and for a job well done. She noted that the

participants had come a very long way and thanked all of the movers and shakers, including the parent advocates. She encouraged everyone to keep going and to have a safe trip home. The meeting was adjourned.

## Wednesday, May 10, and Thursday, May 11, 2006—Breakout Sessions

### Mental Health Treatment Strategies That Work

**Moderator:** Felisha Dickey, MSW, MPA, Coordinator of Human Services, Florida Department of Health; NAFSC Member; 2006 BFSS Planning Committee Member

**Speaker:** Paula Lockhart, MD, Associate Professor of Psychiatry, Kennedy Krieger Institute

Dr. Lockhart began by stressing the need to educate clinicians so that they understand the cognitive profile of children with FASD. Diagnosis-driven evaluation provides the context of the behavior and emotional symptoms rather than making a diagnosis (e.g., ADHD) in isolation. At her clinic, tackling cognitive factors, environmental conditions, susceptibility to behavioral and emotional reactivity, and genetic predisposition for psychiatric disorder requires an integrated context-oriented approach, and patient needs are adjusted from session to session. She discussed the need to anticipate that cognitive changes associated with FASD can influence medication management in terms of “break-through” symptoms that may occur. Dr. Lockhart provided a case overview of a child in her system of care, where the following factors were all assessed:

- History of present illness
- Developmental history
- Social history
- Educational history

The course of treatment that eventually resulted in overall improvements included:

- Psychotherapy
- Psychopharmacology
- Occupational therapy evaluation and treatment
- Speech and language evaluation and treatment
- School intervention
- Social service involvement
- Temporary foster care placement
- Court intervention
- Creating individual education plans (IEPs)



**Speaker: Therese Grant, PhD**, Research Assistant Professor, Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine; Director, Fetal Alcohol and Drug Unit; Director, Washington State Parent-Child Assistance Program

Dr. Grant discussed the variability that is the hallmark of FASD and noted that there is no one-size-fits-all solution for treating children with FASD because each affected individual has a different neuropsychological profile. She also stressed the importance of reminding parents, caregivers, and others that behaviors of children with FASD are not willful, but rather, a result of brain damage. Reminding people that FASD cannot be “cured” can sometimes help to reframe the challenges.

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*There is no one-size-fits-all  
solution for treating children  
with FASD*

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Dr. Grant suggested that neuropsychological evaluations can be very helpful. For treating the primary mental health problem, her strategy is direct therapeutic intervention. For secondary mental health problems, the strategy is comprehensive prevention intervention, which is providing comprehensive and multisystemic support.

Dr. Grant provided an overview of the Fetal Alcohol Syndrome Consultation, Education, and Training Services, Inc. (FASCETS) program, which involved a team of 12 individuals who worked with school-age children, including the child’s bus driver and the school janitor. Team members were taught about FASD and learned each child’s strengths and how to set up a structured, comforting environment for the child. She also provided an overview of the PCAP Double Jeopardy Project, including treatment strategies, and a discussion on the need to educate providers in the community.

### Questions and Comments

A participant inquired about the cost of neuropsychological evaluation. Dr. Grant noted that if court systems and judges were educated about FASD, they may be more likely to order evaluations, and social services would have to pay for them. Another participant asked how the presenters would deal with providers who only treat signs and symptoms instead of determining the source of the difficulty. It was suggested that providers be reminded to look at the long-term picture; for example, what will happen to the child after graduation? In a sense, this is trying to get the providers not just to offer treatment, but also to recognize brain dysfunction, if present. Questions about the PCAP Double Jeopardy project led to a discussion about funding based on outcomes; the PCAP advocate program has demonstrated a cost savings. Dr. Grant discussed the finding that each advocate in this program could accommodate a caseload of approximately five women. Lastly, there was some discussion about the high cost of and difficulty in finding neuropsychological evaluations (cost and access vary by State). Both presenters ended by confirming the importance of the entire family as the core of interventions.



## Screening, Identification, and Referral in Juvenile Courts: A Work in Progress

**Moderator: Barbara Oliver, BSN, CRNP**, Project Director, Alabama FASD Initiative, University of South Alabama; State Subcontractor; 2006 BFSS Planning Committee Member

Each speaker for this session was affiliated with an FASD Center for Excellence subcontractor.

**Speaker: Susan Carlson, BA, JD**, Project Director and Judicial Officer, Hennepin County District Court, Minnesota; Juvenile Court Subcontractor

Ms. Carlson began by describing the work taking place under the juvenile court subcontract. The Hennepin County Fetal Alcohol Specialty Division in Minnesota is part of Project Support. In 2006, the first year of implementation, the project was using screening recommendations from the Expert Panel on Screening in the Juvenile Court and seeing more biological mothers than anticipated. Some of the preliminary results from January 9 to May 8, 2006, showed that 185 juveniles had been screened; 12 evaluations had been completed; 5 youth were diagnosed with pFAS; and 19 youth were awaiting FASD evaluation or the results of evaluation.

Ms. Carlson discussed the following challenges:

- Getting prenatal alcohol history prior to establishing a relationship
- Getting cooperation from an at-risk population
- Ensuring that parents understand the Adaptive Behavior Q's
- Keeping clients during the waiting time between screening and evaluation
- Working with youth with limited family/community support
- Meeting ongoing training needs

Ms. Carlson closed with a success story. One youth, diagnosed with pFAS, is now receiving appropriate treatment in a residential facility. He expects to take the general education development (GED) test and become a mechanic.

### Questions and Comments

Ms. Carlson clarified that her project is not a research study, although it does collect data. In response to a question, she described the FAS Facial Photographic Analysis Software, which is used as both a screening and diagnostic tool, and the training given to sites to enable them to use it. Several questions were raised about payment for evaluations. Ms. Carlson noted that even when a judge orders an evaluation, it does not mean that the agency will pay for it. The cost of the evaluation to the family is sometimes a barrier to services.



**Speaker: Eileen Bisgard, JD**, Project Director, FASD Initiative of the 17th Judicial District Juvenile Court, Adams County, Colorado; Juvenile Court Subcontractor

Ms. Bisgard described the implementation phase of the subcontract in the 17th Judicial District, Adams County, Colorado. The plan was to phase in FASD screening in the Truancy Court in November 2005, followed by the Delinquency Court in January 2006, and concluding with the Child Protection Court (Dependency and Neglect) in September 2006. The initiative uses the screening recommendations of the Expert Panel on FASD Screening in the Juvenile Court.

Adams County has a child development center that provides FASD diagnostic services. The center's team includes a developmental pediatrician, clinical psychologist, occupational or physical therapist, and a speech therapist. Ms. Bisgard described the programs and processes of the various courts. The Truancy Court does not have the jurisdiction to order an FASD screening, so FASD screening there is voluntary. In November 2005, a battery of questions was asked at intake. There were six intakes in 3 weeks with two positive screens (30 percent). In December, the questions related to problem drinking history were moved to a separate intake sheet. Since December, there have been four intakes and four positive screens (100 percent). Staff have learned better methods to get cooperation from the schools. The diagnostic team goes to the schools, and school staff can attend feedback sessions. Staff who work directly with the children are supportive of the initiative.

In the Delinquency Court, probation officers include FASD screening questions in their intake interviews, take facial pictures, and e-mail the results to the FASD team. The subcontract team trained court staff on screening techniques, including interviewing and taking the facial pictures, and provided a review of the FASD basics. Clear communication has been established between the probation office and the FASD team.

"FASD Screen and Recommended Treatment Ordered" is stamped on pre-sentence investigation orders, probation orders, and conditions of probation. The court clerk makes sure that the judge or magistrate remembers to order the screen. The process takes about a month from order to receipt. The FASD team runs the facial software, documents information on the child, and checks the mother's legal history for indicators of alcohol and drug use. When screens are positive, an FASD intervention specialist contacts the family and does a home visit to develop a relationship and begin to collect information for the evaluation.

After a positive screen, the diagnostic team is notified. The FASD team collects birth and medical records; IEP information, especially test results; and any other evaluations that are available. When all of the information is gathered, youth are scheduled for a 4-hour evaluation. A brief feedback session is held for parents, FASD staff, the probation officers, and school staff. Within 30 days, a more extensive report is received. The FASD staff work with all of the people and agencies in the child's life to help them learn intervention techniques. Parents are invited to a parent support group and offered additional training. To date, no parents have opted to participate in the support group. Stigma and concern over possible future consequences are issues, though the



magistrate has told parents that records can be sealed. If the evaluation is completed in time, the results of the evaluation may be included in the pre-sentencing investigation report. Probation officers are receptive to modifying their plans to accommodate the youth.

Since April 21, 2006, 100 youth on probation have been screened and 28 (28 percent) screened positive for an FASD. During that time, one diagnostic evaluation was completed. There have been many lessons learned. Probation officers do not obtain consistent information, and it is sometimes difficult to get information at intake when a relationship has not been established. Probation officers only see their charges once a month, and there is a need for developing ongoing support systems and training.

In Dependency Court to date, seven children have been referred by the court, two (28.6 percent) have screened positive, and no diagnostic evaluations have been done. Broad screening will not occur until September 2006.

**Speaker: Trisha Colwell, MEd, PCMHT**, FASD Project Director, Mississippi Department of Mental Health; NAFSC Member; State Subcontractor

Ms. Colwell outlined distinctions and similarities in her subcontract with the earlier presenters. The Adolescent Offender Program (AOP) is a statewide program in Mississippi that provides treatment to juvenile offenders 12

to 17 years of age and is a community-based alternative to incarceration. Counseling services are provided in a therapeutic setting and are coordinated with other service providers.

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*The Adolescent Offender Program (AOP) is a community-based alternative to incarceration*

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Youth are referred to AOP by court order and are required to successfully complete all requirements or risk incarceration. AOP is a three-phase program that operates year round. Participation in AOP is limited to approximately 12 months. Five therapeutic modalities are used: (1) day treatment, (2) group counseling, (3) individualized counseling, (4) socialization skills, and (5) family intervention.

FASD screening is part of the AOP intake process. It includes psychosocial evaluation, history and records review, prenatal alcohol exposure questionnaire, FASD behavioral checklist, and an FAS facial photographic analysis. The University of Mississippi Medical Center (UMMC) Child Development Clinic uses a multidisciplinary team to provide diagnostic evaluations.

Following diagnosis at UMMC, adolescents diagnosed with an FASD will have an updated treatment plan that includes recommendations by the UMMC diagnostic team. Making a Plan (MAP) Teams provide services through interagency case review teams located throughout the State. In 2005, Mississippi legislature mandated a statewide system of care for children and youth with mental health needs. These local MAP Teams work in partnership with families to develop a personalized plan for each child. When an adolescent leaves AOP, aftercare/transition services will be devised and monitored via the MAP teams. Adolescents and families often have a good understanding of delinquency but have difficulty grasping the mental health issues.



## Questions and Comments

Questions were raised regarding the use of the Massachusetts Youth Screening Inventory (MAYSI) assessment tool. Minnesota and Mississippi mandate the use of the MAYSI. There was discussion about the validity of a mental health diagnosis as opposed to an FASD diagnosis. The FASD initiatives in Minnesota and Mississippi are located in clinics that serve adolescents with mental health problems.

## Integrating Multidisciplinary Diagnostic Centers in Systems of Care

**Moderator:** Vivian Gettys, BSN, MA, MPH, FASD Project Manager, Capital Area Human Services District; Local Community Subcontractor; 2006 BFSS Planning Committee Member

**Speaker: Leslie Evans, MS,** Director and FASD/Teratology Specialist, North Carolina Teratogen Information Service, Fullerton Genetics Center; NAFSC Member; FASD Center for Excellence Field Trainer; Local Community Subcontractor

Ms. Evans discussed multidisciplinary versus interdisciplinary clinics. Mission Hospital, a trauma hospital in Western North Carolina, provides the only genetics clinic in the area. One of the first tasks for the project task force was to determine whether to develop a multidisciplinary clinic, with specialists located in the same place, or an interdisciplinary clinic, where an initial assessment is completed and the family is referred to specialists for further assessments. Through research, it was determined that the multidisciplinary clinic was the better option. In the multidisciplinary clinic approach, the patient moves through all the clinicians in 1 day—possibly even 2 to 3 hours—and can potentially leave with a diagnosis and a plan for treatment. However, after observing other multidisciplinary clinics, it was determined that the appointment for the family generally takes significantly longer than 2 to 3 hours, and the child's attention is limited toward the end of the day. Potential issues included finding space to house all the clinicians, billing for services, and determining whether children that do not receive a diagnosis would return to the geneticist for further evaluation.

After considering these findings, a decision was made to develop an interdisciplinary clinic. An appointment lasts 2 hours, with the family spending the first hour with the medical geneticist and clinic coordinator, who also serves as the genetic counselor for diagnosis. The second hour is spent with the parent navigator, who helps families work through the system, and the FASD specialist, who provides information on FASD and will participate in future meetings with the family, including the development of an individualized education program (IEP). When indicated, families are referred to a developmental pediatrician, a neuropsychologist, a speech therapist, or an occupational therapist.

Parents requested that the clinic not emphasize facial features. The FAS Facial Photographic Analysis software will be used for diagnosis, not screening. The parent advocates suggested that the team attend Diane Malbin's training, which is offered four times a year. The professionals were receptive to the suggestion and, to date, over 200 professionals have been trained (the original goal was 100). Information on the training can be found on the FASCETs Web site, [www.fascets.org](http://www.fascets.org).



The interdisciplinary clinic's clientele is predominantly white. Staff dress casually to create a more relaxed atmosphere for the children and their families. Currently, there is no parent support group, but there is a plan to create one.

Ms. Evans recommended a 40-page FASD primer, *Fetal Alcohol Syndrome: A Parents Guide to Caring for a Child Diagnosed with FAS*, to provide parents with some basic information on FASD. The document is written at a 6th-grade level and can be downloaded for free from [www.otispregnancy.org/pdf/FAS\\_booklet.pdf](http://www.otispregnancy.org/pdf/FAS_booklet.pdf).

**Speaker: Susan Rich, MD, MPH**, Fellow, Department of Psychiatry, Children's National Medical Center

Staff at the Children's National Medical Center clinic see 1,000 new patients a year. Dr. Rich assesses as many as 2 to 3 patients with FASD a month. When parents call to make an appointment, the receptionist asks questions to screen for prenatal alcohol exposure. Dr. Rich provided an overview of comprehensive new patient evaluations. The evaluations include:

- Obtaining and reviewing prior testing/assessments, if possible before the appointment.
- Meeting with the parents and child for a diagnostic interview/history. New patient evaluations take approximately 2 to 3 hours.
- Making referrals for other specialty assessments.

Dr. Rich modeled her assessment tool on a comprehensive questionnaire used to address relevant domains. The dimensions of an FASD neuropsychiatric evaluation include:

- Cognitive development
- Motor skills
- Social interactions
- Quality of attachments
- Communication abilities
- Behavior
- Learning problems
- Self-image
- Self-regulation (sleep, appetite, emotional regulation)
- Autonomy/independence and activities of daily living
- Academic performance
- Screening for Axis I and II diagnoses



Regarding treatment strategies, Dr. Rich suggested having a nonjudgmental discussion with the parents that includes providing support and educational materials to help both the child and family, as well as discussing the child's strengths. Strategies include participating in social skills groups; assisting families, teachers, and therapists in identifying appropriate expectations; and providing structure at home, in school, and in social environments. Dr. Rich closed by stressing that families should receive counseling to assist them in meeting the challenges of raising a child with an FASD.

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*Families should receive counseling to assist them in meeting the challenges of raising a child with an FASD*

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**Speaker: Georgiana Wilton, PhD**, Associate Scientist, Department of Family Medicine, University of Wisconsin School of Medicine and Public Health; FASD Center for Excellence Field Trainer; Local Community Subcontractor

Dr. Wilton said that it is critical to determine what services and models are available and needed to meet the needs of families. First steps include identifying partners and competitors. To turn competitors into partners, learn what services other groups or agencies do not offer, and collaborate to offer a greater number of services. Locate FASD experts to help with navigation through various systems, identifying gaps along the way. A unique component of the University of Wisconsin's program, in addition to the multidisciplinary clinic, is the family advocacy program. Called the Family Empowerment Network, it offers a wide range of services to families with children affected by an FASD.

If a multidisciplinary clinic is needed, certain questions must be answered:

- What information do you have that identifies this need?
- How many individuals are at risk for FASD?
- Can they be served without you?
- What unique component can you provide? (The answer can support sustainability.)

Identifying the goal for the clinic provides boundaries on the number of clinicians and the extent of the assessment. Reaching consensus on the components of a comprehensive assessment can be challenging. The University of Wisconsin clinic has eight clinicians. Assembling the team is critical and provides the framework for the assessment process.

After the clinic's goals are identified, determine what can be done before and after clinic hours to use clinic time and space most efficiently. Plan a realistic schedule with the number of clinic days, number of patients per clinic day, and the flow of the clinic day to allow for adequate time for assessment, scoring, and reporting. In addition, plan for a timely distribution of the summary report.

A critical step is the determination of the diagnostic criteria. The University of Wisconsin uses the Institute of Medicine's criteria for diagnosing FAS, ARND, and ARBD. Marketing decisions



depend on the extent of the need and the possible number to be diagnosed per year. If funding permits, try to waive fees for families that are unable to pay.

In closing, Dr. Wilton noted that it is critical to plan ahead for sustainability by developing a plan early on to sustain efforts after the funding ends. Identify alternate sources of funding through research and training grants or through private foundations. Encourage research and evaluation as positive results confirmed through evaluation open up more funding options. Finally, Dr. Wilton stressed the need to keep clinicians happy and to be patient.

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*Keep clinicians happy and to  
be patient*

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### **Preventing FASD: Promising Practices from the Field**

**Moderator: Jerome Romero, BA**, Principal Investigator, Statewide Fetal Alcohol Syndrome Prevention Project, University of New Mexico Center on Alcoholism, Substance Abuse, and Addictions; FASD Center for Excellence Steering Committee Member; NAFSC Chairperson; 2006 BFSS Planning Committee Member

**Speakers: Melinda Norman, BS**, Prevention Coordinator, Ohio Department of Alcohol and Drug Addiction Services; State Subcontractor

Ms. Norman began with a discussion of the Not a Single Drop Web site, [www.notasingledrop.org](http://www.notasingledrop.org), Ohio's online resource for FASD in support of a comprehensive State system of care. She also gave a brief overview of the FASD initiative and task force. Their goals are to:

- Increase the availability of services for those affected by FASD and for their parents and other caregivers.
- Increase awareness regarding the risk associated with alcohol use during pregnancy.
- Provide FASD-specific education and training for agencies, organizations, and professionals who provide services to children and families with or at risk of FASD.
- Adopt appropriate FASD screening tools and protocols.
- Increase access to screening.
- Create and implement a data tracking system to track FASD risk factors, prevalence, and incidence in Ohio.
- Measure progress toward reaching other FASD prevention goals.

**Kathy Paxton, MS**, Director of FASD Initiatives, Ohio State University Center for Excellence

Ms. Paxton explained the importance of using the Partnership for Success, an evidence-based planning process critical for developing policies and practices. On the Not a Single Drop Web site, Ohio has included keys to working successfully with children prenatally exposed to alcohol, including an outline for structure: consistency, brevity, variety, and persistence. They offer links to lesson plans and curricula for parents and educators.



**Speaker: Margo Singer, MPA**, Addictions Program Specialist II, New York State Office of Alcoholism and Substance Services; State Subcontractor

Ms. Singer began with an overview of New York's statewide FASD Prevention Initiative. She pointed out that the goal of the initiative is to reduce the number of cases of FASD by eliminating alcohol consumption by pregnant women. She described how the initiative convened a statewide task force, conducted a needs assessment, and developed a strategic plan that included implementation and evaluation. It seeks to create a State-level administrative focus, provide for long-term or sustained funding of FASD services, develop FASD policies and procedures, integrate FASD services into the service delivery system, and organize ongoing surveillance and evaluation of the services.

The FASD initiative targets women of childbearing age, pregnant women, and women at risk for an alcohol problem. New York State's FASD task force developed a program and policy action plan that included public awareness, Office of Alcoholism and Substance Abuse Services systems collaboration, surveillance, and education and training. It identified three sites for FASD intervention. The prevention project will use motivational interviewing, alcohol screening, brief interventions, and referral to family planning for more effective contraceptive methods.

Ms Singer presented outcomes from the three pilot sites where FASD prevention has been implemented. Initial findings from the sites included the following:

- Motivational interviewing techniques fit well with a strengths-based approach to working with families in many problem areas.
- Use of motivational interviewing can be a challenge for traditional addiction treatment counselors.
- Men and non-childbearing women are also interested in FASD information.
- Some women were surprised that their drinking placed them at risk

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*Some women were surprised  
that their drinking placed  
them at risk*

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**Speaker: Susan Gadacz**, FASD State Coordinator, Bureau of Mental Health and Substance Abuse Services, Madison, Wisconsin Department of Health and Family Services; NAFSC Member; State Subcontractor

Ms. Gadacz began with an overview of PRAMS data, which indicate that Wisconsin leads the nation in alcohol consumption by women aged 18 to 44 (68 percent). The goal of the Wisconsin FASD prevention project is to prevent FASD through prevention activities that increase the number of women who do not drink alcohol while pregnant. Wisconsin has developed a similar program for smoking cessation. The project is named My Baby & Me. It focuses on healthy pregnancies and uses a relational/cultural model, informal supports, and community resources for the intervention. Project staff developed a workbook that emphasizes the following:



- Why women should stay alcohol-free
- How to identify high-risk situations
- How to handle especially difficult situations
- How to handle stress, anxiety, and depression

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*Wisconsin leads the nation in alcohol consumption by women aged 18 to 44*

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The curriculum also addresses anger and fear, postpartum concerns, and further steps for additional assistance, if required.

Staff assess effectiveness of the intervention on a regular basis and obtain feedback from prenatal care coordinators and mothers to improve the project. The My Baby & Me project plans to expand to other sites and seeks specifically to address alcohol and other drug treatment programs.

### **An Ideal System of Care for Individuals with an FASD**

**Moderator: Barbara Wybrecht, RN, BSN**, FASD Clinical Nurse Specialist, Spectrum Health; FASD Center for Excellence Field Trainer; 2006 BFSS Planning Committee Member

**Speaker: Teresa Kellerman, BA**, Director, FAS Community Resource Center; NAFSC Member; FASD Center for Excellence Field Trainer; 2006 BFSS Planning Committee Member

Ms. Kellerman began with a quote from her son, John:

*Sometimes I function at the level of a 4-year old, sometimes I function at the level of a 14-year old, and sometimes I function at the level of a 24-year old. I can't predict or control my level of function, and that is scary.*

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*No single system can address all the needs of an individual with an FASD*

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Speaking as the mother of a son with FAS, who has benefited from appropriate services throughout his life, Ms. Kellerman described an ideal system of care. She noted that no single system can address all the needs of an individual with an FASD. Instead, the ideal is to prepare and train each existing system that may be needed in the course of an individual's life to respond appropriately.

These systems include:

- *Diagnosis*: Early identification is important as a protective factor against unfavorable outcomes.
- *Medical/health care*: Meet varied needs, which can include addressing health issues and providing appropriate therapies (e.g., physical, occupational, speech).
- *Foster care*: Provide training in child development and attachment issues.
- *Education*: Early intervention preschool, special education classes, individualized education and transition plans, and vocational training.
- *Developmental disabilities*: Borderline IQ, case managers, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), respite care, and residential services.



- *Mental health:* Find an appropriate Axis I diagnosis for services (e.g., ADHD, Impulse Control Disorder.)
- *Criminal justice system:* Provide developmental disability training to new police officers and the appropriate courts (e.g., drug and family).
- *Substance abuse prevention:* Substance abuse prevention is an identified protective factor. Risk assessment, awareness education, and treatment programs are all needed.

Ms. Kellerman stressed that successful outcomes depend on strong family and consistent parenting; a reality-based awareness on the part of the individual with an FASD, with acceptance of limitations; and the need for a protective environment. Systems must develop the talents and natural gifts of individuals with an FASD with the expectation of providing a lifelong circle of support. Also, a strong support system for the parents and caregivers of the individuals is necessary.

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*Systems must develop the talents and natural gifts of individuals with an FASD*

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Ms. Kellerman closed with a vision of an ideal system of care: Every person in every system is trained in FASD issues, understands the nature of FASD as a neurological impairment, can recognize the symptoms of invisible forms of FASD, and can see the difference between apparent ability to function (chronological age) and actual ability to function (much younger).

**Speaker: Rob Wybrecht**, Lifelong Expert on FAS; FASD Center for Excellence Steering Committee Member

*Tell me and I will forget; show me and I may remember; involve me and I will understand.*  
~ Chinese proverb

As an individual with FAS, Mr. Wybrecht shared his real-life experiences and specific examples of the types of day-to-day supports that are needed. He also presented obstacles he has dealt with and introduced alternatives to some current expectations.

Mr. Wybrecht suggested that parents who regularly attend FASD-related support groups and workshops, who support and encourage self-advocacy, and who are comfortable with the fact that they will forever be parenting a child/adult with an FASD are the strongest protective factor against secondary disabilities.

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*Parents are the strongest protective factor against secondary disabilities*

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Parents and caregivers need to be prepared to advocate for needed support from the various systems that will affect the life of their child/adult with an FASD. Rather than focusing on independent living, emphasis should be placed on interdependent living. He suggested finding living situations in which individuals with an FASD could be paired in housing with individuals who have physical impairments (i.e., elderly or physically disabled) to help each other with strengths and weaknesses.



The adult with an FASD will need:

- Ongoing love and support from parents and extended family
- Knowledge that he or she is truly loved and always respected
- Person-centered planning/adult wraparound services
- Ongoing experiences in the larger community
- Job coaching and other vocational support
- Designated payee and/or assistance with money
- SSI and/or SSDI
- Supervised “independent” housing
- Safe, supervised social events
- A life coach (i.e., a therapist who is there for the long term and listens carefully)
- Concrete classes on health, nutrition, safety
- Regular physical recreation
- Substance abuse treatment from therapists who understand FASD
- A criminal justice system that understands that brain differences impact understanding, memory, and behavior

Concrete tools to help people with FASD include:

- Vibrating watch, organizer, or cell phone to set alarms with reminders
- Clock
- Foam earplugs
- Big clear box for regularly used items like watches, wallets, and car keys
- Notebooks with the jobs for the day
- Laminated map of what needs to go where in a job (example was shown of the layout of a salad bar)
- Wallet cards to show if stopped by the police

In closing, Mr. Wybrecht stressed that long-term life planning should begin as early as possible. This includes trust funds, person-centered wraparound services, and services that may not currently exist but must be creatively developed. Most importantly, individuals with an FASD must be included in this planning. Their understanding and acceptance of their own strengths and weaknesses will be necessary to the successful implementation of life planning and support.



## Connecting with Tribes and Native American Groups to Strengthen State Systems

**Moderator:** Candace Shelton, MS, LISAC, Senior Native American Specialist, Johnson, Bassin & Shaw

**Speaker:** Suzie Kuerschner, MEd, FASD Consultant/Trainer, Northwest Portland Area Indian Health Board/Strategies for Prevention, Intervention, Resilience in Teaching for Success; American Indian/Alaska Native/Native Hawaiian Stakeholder

Ms. Kuerschner presented a discussion on Circles of Collaborative Care. She started the session explaining that there are more prevention materials, program curricula, and trainings focusing on FASD interventions coming from American Indians than from any other ethnic group. She stressed the need to combine traditional and clinical perspectives. One traditional Indian prophecy suggests “there will come a time when there would be those born who would look different, and with these differences there would come a message that would change the people.” This prophecy frames children with FASD positively and provides great opportunities for teaching and discussion.

Ms. Kuerschner explained how tribal and county services working collaboratively could create powerful prevention and intervention models that reflect community strengths. One of the many beliefs of Native Americans is that each individual is responsible for looking after and protecting the next seven generations. She explained that promoting that belief among Native Americans supports the efforts of integrating knowledge and prevention for healthier families and healthier futures.

Ms. Kuerschner noted the following needs:

- To focus prevention efforts on Native prophecies, beliefs, values, traditions, strengths, cultural and spiritual perspectives, and diversity
- To use a clinical approach to learn about FASD and related conditions and their impact on physical, cognitive, social, and emotional abilities
- To understand manifestations of behavioral characteristics and cognitive processing

She also discussed some common challenges and vulnerabilities for people with an FASD:

- Difficulties with making transitions and problem solving
- Inability to predict what will happen next
- Sociability to the point of vulnerability
- Feelings of failure that may lead to depression and/or mental health and substance use issues
- Frustrated communication that can end up in tantrums, ODD, and involvement in the justice system



- Difficulties in processing memory and cognition, often leading to school and job failure
- The need for social reinforcement and physical reinforcement, which sometimes leads to inappropriate sexual behaviors

Ms Kuerschner explained that integrating FASD interventions now will result in prevention for future generations. She gave examples of building blocks for successful prevention and intervention strategies, including:

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*Integrating FASD  
interventions now will result  
in prevention for future  
generations*

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- Understand behavior as communication and identify strengths and skills that can be applied and used to address the particular needs of the situation.
- When working with Native people, remember to “show” rather than “tell.”
- Understand the need for structure, a calm environment, and consistency.
- Create positive behavioral maps.
- Understand the ramifications of “concrete processing.”
- Beware of “ceilings of expectation” and “never” statements. Remember to assist with generalization.
- Have realistic expectations. Build for success. Know that early identification and early intervention are keys to future success.
- Know that it is never too late to provide successful strategies.
- Understand how prevention and intervention are reciprocal.
- Create collaborative provider partnerships and multidisciplinary consortiums that create circles of coordinated care.

Ms. Kuerschner closed by explaining that women do not drink to harm their unborn children and that mothers, fathers, aunts, uncles, grandmothers, and grandfathers all want healthy families. Women drink to mask feelings of failure, to medicate the pain of past and present abuse, and to make the environment less intrusive. She explained that effective intervention models for pregnant women using alcohol should include everyone in the women’s sacred circle of life, which is composed of community, extended family, mother, father, and baby.

**Speaker: Violet Mitchell-Enos, MSW**, Executive Director, Department of Health and Human Services, Salt River Pima-Maricopa Indian Community; American Indian/Alaska Native/Native Hawaiian Stakeholder

Ms. Mitchell-Enos gave a presentation on connecting with tribes and Native American groups to strengthen State systems. The Pima County Department of Health and Human Services is committed to children and elders and is working to integrate all of its services to better serve the



community. As of July 2005, there were 8,030 enrolled members in the Salt River Pima-Maricopa Indian tribe. Of those members, approximately 4,750 live on the reservation, and others live inside or outside the Phoenix metropolitan area. There were 46 more births than deaths in 2004. For 2004 and the 4 proceeding years, the average age of death for the Maricopa Indian Community was 46.6. For other tribes in Arizona, the average age of death was 55.4, and for all ethnic groups in Arizona, the average age of death was 71.6. Because of these statistics, the community decided to develop a 20-year strategic plan to:

- Decrease substance abuse
- Decrease diabetes
- Increase the average age at death

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*If substance abuse is not addressed, tribal communities will be negatively impacted by lack of leadership and economic hardship*

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If substance abuse is not addressed, tribal communities will be negatively impacted by lack of leadership and economic hardship. Tribal communities are small in comparison to the overall communities. Their members, like everyone else, are interested in caring for their families and the land. People affected by an FASD often require services to address their individual needs. The Salt River Pima-Maricopa Indian community is experiencing escalating educational costs because of the expense of helping children with an FASD to succeed in school. They have also seen an increase in out-of-home placements of children that parents say they cannot manage. Some of the placements have been outside of the reservations, which disconnects the children from their culture, tribe, and family. As the Salt River Pima-Maricopa Indian community deals with issues related to FASD, it has discovered that it needs more data (e.g., how many individuals are affected with FASD?), more education (e.g., what are FASD and FAE?), and better access to services and funding.

Ms. Mitchell-Enos ended her discussion by noting several challenges, including decreased Federal funding; a need for increased services and programming that is culturally specific; and support for community-based approaches, institutionalized programming, and transportation. Salt River would like to see the larger community work together by establishing partnerships, providing education at all levels, and advocating for increased funding and program development that meets the needs of the communities.

**Speaker: Lorena J. Burris, PhD**, Education and Training Specialist, Center for Child Abuse and Neglect, Oklahoma University Health Sciences Center; American Indian/Alaska Native/Native Hawaiian Stakeholder

Dr. Burris began with an overview of the Indian Country Child Trauma Center (ICCTC). The ICCTC is an organization that seeks to improve treatment and services for Native children and adolescents in Indian Country who have experienced traumatic events. Its mission is to raise the standard of care and improve access to services for traumatized children, their families, and communities throughout Indian Country. Indian Country is legally defined as all land within the limits of any Indian reservation under the jurisdiction of the United States Government, all



dependent Indian communities within the borders of the United States, all Indian allotments, and the Indian titles that have not been extinguished. She continued with a breakdown of the American Indian and Alaska Native population from the 2000 census:

- Approximately 2.5 million people self-identified as American Indian or Alaska Native in the 2000 Census.
- Approximately 4.1 million American Indians and Alaska Natives identified as one or a combination of one or more races.
- Approximately 38 percent of the American Indian and Alaska Native population is under the age of 18.
- Approximately 9 percent of the American Indian and Alaska Native population is under the age of 5.

Dr. Burris explained differences between the beliefs of American Indians and Western societies. She pointed out that American Indians believe in sharing, cooperation, being, the group, and harmony with nature, while Western societies focus on saving, competition, doing, the individual, and mastery over nature. It is important for American Indians to preserve cultural identity, maintain a strong cultural foundation, show respect for elders, place value on children, and understand extended family structure.

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*It is important for American Indians to preserve cultural identity, maintain a strong cultural foundation, show respect for elders, place value on children, and understand extended family structure*

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Dr. Burris explained that culture changes are taking place in Native communities due to domestic violence, child abuse and neglect, substance abuse, mental disorders, unintentional violent deaths, and suicide. To address these issues, they have developed prevention strategies that will work on three levels. Primary prevention is directed at the general population and involves raising awareness and providing education. Secondary prevention is directed toward high-risk groups and seeks to prevent or minimize harm. The third level, tertiary prevention, focuses on reducing problematic behavior and involves treating the problem to lessen its effects.

Also discussed was the impact of assistance from non-Native organization and how it can create barriers to prevention. When outside organizations come into Native communities to provide services, they sometimes present with a lack of cultural knowledge and sensitivity, as well as attitudes of superiority and prejudice. These outsiders may face language barriers and distrust. She noted some of the obstacles that deter tribal members from seeking assistance:

- Lack of consistency
- Lack of professionals with specialized training
- Territorialism



- Lack of confidentiality
- Tribal/agency politics
- Isolation
- Limited services
- Excessive paperwork to receive services
- Waiting periods for service delivery
- Stigma/shame
- Substance abuse
- Resistance to change

Dr. Burris suggested the following strategies to outside agencies wanting to implement prevention programs in Native communities: wait until assistance is requested, be aware of “cultural trespassing,” establish trust with the community, and be respectful. Once an agency has been accepted to work within the Indian community, it should seek support from community leaders, introduce community members to the new programs and providers, enforce sanctions for breach of confidentiality, address the younger population, use the tribal elders, and promote the cultural strengths.

### **State Policy Approaches for Addressing and Treating Individuals with an FASD**

**Moderator: Gilbert Sudbeck, MS**, Division Director, South Dakota Division of Alcohol and Drug Abuse; State Subcontractor; NAFSC Member

**Speaker: Kathryn Kelly, BA**, Project Director, FAS/E Legal Issues Resource Center, Fetal Alcohol and Drug Unit, University of Washington; Local Community Subcontractor

Ms. Kelly provided an overview of the Division of Developmental Disabilities, whose services are key in preventing secondary disabilities. Services can include a case worker, job coach, health care, or financial help. Applying for DDD benefits is a multistep process that would be virtually impossible for anyone needing the services to complete alone. Ms. Kelly noted the importance of accessing the Office of Protection and Advocacy or a private attorney to apply for services and generally help individuals navigate the system. The process, which takes time and persistence, requires an explanation of the cause and nature of the disability and the reason why the individual cannot hold a job. Eligibility varies by State.



**Speaker: Steve Bruce, JD**, Executive Director and Managing Attorney, People With Disabilities Foundation, Inc.

Mr. Bruce discussed the Social Security system and the process for attaining benefits. He suggested that if a person is denied initially, he/she should consider working with an attorney to help navigate the complex system. He noted that the rules for children are different and much more complex than those for adults. For children, there is a three-step process for eligibility, including meeting the medical listing, meeting the IQ range, and meeting the functional equivalent of the listing. To be considered for eligibility, a child must rank “marked” status, which falls in between moderate and extreme. Mr. Bruce explained that although the Social Security Administration does not distinctly recognize FAS, it does recognize a combination of disorders. He also encouraged participants to make use of their State Developmental Disabilities program.

**Speaker: Susan L. Ball, MA, JD**, Attorney, Michigan Protection and Advocacy Service, Inc.

Ms. Ball spoke about the Michigan Protection and Advocacy for Individuals with Disabilities system, which was established through Federal legislation (though the name varies by State). Individuals from the protection and advocacy system can go to court hearings and represent individuals and can also pull records independent of Government authority. Not all offices offer the same services, but even if an office cannot take a case, it will provide advice to interested parties. The main purpose of the system is to help parents get needed services for their children. Staff will not help clients who are already accessing services from other resources, and there must be a legal argument that can be made for them to take a case. For example, if a child with an FASD is expelled from school for possessing marijuana, a case could be made based on poor judgment or impulse control associated with FASD. The offices also work on policy advocacy and provide workshops and seminars. In closing, Ms. Bell urged participants to contact their protection and advocacy branch to ask them to make FASD a priority area.

**Speaker: L. Diane Casto, MPA**, Manager, Prevention and Early Intervention Services, Division of Behavioral Health, State of Alaska; FASD Center for Excellence Steering Committee Acting Co-Chairperson; NAFSC Member

Ms. Casto shared her experience with Alaska’s FASD diagnostic team network, including the challenges of bureaucracy, regulation, and policies at the State and Federal levels. Change in Alaska began with a summit for parents, educators, clinicians, etc, which resulted in the Office of FAS. This office examined policies and practices in Alaska concerning FAS and eventually developed a system of 12 community-based diagnostic teams, including one specialty team at the Alaska Psychiatric Institute. These teams were built into existing structures and were funded less and less each year so they would not become dependent on the funding. Each team included a parent navigator who had actually navigated the system and was trained to assist other parents to do so. The diagnostic team network has had success with over 850 completed diagnoses since 2001 and solid prevalence numbers to take to the legislature. The diagnostic centers implemented in Alaska are not required by law, but Ms. Casto hopes they will impact policy.